

Barriers to the use of a Personal Health Record by an Elderly Population

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ABSTRACT

Personal health records (PHRs) are proposed as a strategy to make health care delivery increasingly patient-centered. Yet little work has been done in understanding the workflows of patients in their own homes, or influence of access, cognitive, physical, or literacy barriers on workflow and outcomes of using health records. Many populations may require assistance in using PHRs to improve their health outcomes. We studied PHR use by an elderly and disabled population and describe those barriers encountered by our patients.

INTRODUCTION

The United States has a complex, sophisticated health care industry but the delivery of health care is fragmented and decentralized. In 2001, the Institute of Medicine's report, "Crossing the Quality Chasm," identified six aims for improving the quality of health care, one of which was that care should be patient-centered.¹ Gertis had previously identified six dimensions of patient centered care, which have in common the themes of communication of health information and preferences; involvement of the patient, family, and friends; and coordination of care.² These information exchanges may be facilitated by personal health records (PHRs).

The Phase I final report from the Markle Foundation's Connecting for Health collaborative defines a PHR as "an Internet-based set of tools that allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it..."³ The report clearly enunciates the idea that the information crosses organizational boundaries, is a lifetime record, and is patient controlled. Many organizations have used the term more loosely, to mean any system or portal that allows a patient to manage and track their health information. In either case, such information may include personal demographics, medical problems and concerns, past health history including providers and significant events, family history, allergies, medications, and diseases and information such as emergency contacts, provider communications, scheduling, and insurance information. Also, as a system fitting the Markle definition (a "patient-centered" record), or as an institutional system storing information on behalf of the patient (a "patient portal" re-

cord), PHRs may be one way to address a central problem in health care delivery today.

Many factors contribute to the challenges in obtaining timely, complete historical health information in clinical care. These include increases in the mobility both of the population and of their health care providers, and in the complexity of care delivered. Transfers of care are becoming more frequent both in the inpatient and the outpatient settings. Furthermore, recent emphases on bioterrorism, outbreak, and disaster preparedness, as well as recent natural disasters, have highlighted the challenges in maintaining health records. Victims of Hurricane Katrina who were displaced could not refill prescriptions, replace eye glasses, nor did they have any diagnostic tests results available for a new provider. Their medical records were not available because they were paper-based and destroyed in the disaster, or electronically stored at a facility that could not be accessed. This led to rapid development and deployment of health information services based on existing integrated data sources, such as the electronic prescription medication records system www.katrinahealth.org

Yet, little work has been done on the usability of PHRs, on patient preferences for entering, maintaining, and disclosing portions of their record, and on what, if any, assistance may be required to help elderly, disabled, and immigrant populations use PHRs. This last point is particularly important for two reasons. First, the population is aging and traditional care patterns may be strained as the ratio of caregivers to patients changes. Second, disadvantaged and vulnerable populations appear to be disproportionately affected by recent natural disasters, and may suffer greater health impacts from the loss of their health records.

To assess the feasibility of PHRs for a population comprised of elderly, disabled, and immigrant patients, the UW School of Nursing, Department of Bioengineering, and Clinical Informatics Research Group have partnered to develop and implement a web-based, patient-centered, health record at a community-based, federally-funded, housing authority (HA) in a community near Seattle, Washington.^{4,5} The PHR is also being deployed in assisted living facilities in Singapore, to assess cross-cultural translation of feasibility. This later deployment is part of a broader cooperative research project between the

University of Washington and the Nanyang Technological University in Singapore.

STUDY OBJECTIVE

Improved use of information technology is essential to improve the management and delivery of health care. Personal Health Records may be an important tool in changing that care to be more patient-centered. *The objective of this study was to evaluate the barriers faced by a low income, elderly population in creating and using a personal health record.*

BARRIERS

In a recent article, Tang et al. discussed a broad range of barriers to the adoption of PHRs.⁶ They characterized these barriers as “environmental”, including organizational, economic, legal, and privacy concerns; and “individual-level”, including workflow models, behavioral change, and recognition of value by the patient, and challenges to provider autonomy. They make the point that studies of patient workflows in the home are rare, but would be important in understanding how the PHR fits into the lives of the individuals using it.

We believe that, in addition to these barriers, there are a range of individual barriers which may vary substantially in different populations. These barriers may constrain patient workflows around the use of a PHR. For instance, a patient with a physical disability may recognize the benefit from organizing and managing their health information, but may be unable to do so without assistance. A patient with low health literacy may not recognize the benefits without education, but may be able to maintain portions of their record independently after some education. While patients may benefit from decreased costs and improved quality of care, the costs of providing assistance to overcome barriers on some patient populations may further confound the assessment of environmental/economic barriers. To help clarify that, we believe it is important to characterize the level of training and skill set required to assist different types of patients.

General categories of barriers include:

- access to PHR systems
- access to computers or devices
- cognitive disabilities
- physical disabilities
- low computer or reading literacy
- low health literacy

Access to PHR systems is primarily an economic/business model issue discussed by Tang.⁶ Access to computers among different segments of the population has been discussed at length as a “digital

divide”. Despite many studies, this divide is a constantly moving target, but in general access and bandwidth continue to improve for most segments of the population. The elderly and disabled low-income residents of the subsidized housing projects with which we work have clusters of broad-band connected computers available for their general use.

Cognitive function is an issue for many people over the age of 65, and may impact their use of a PHR. Memory impairment affects 11% of women over the age of 65 and 15% of men in that age group had moderate to severe impairment.⁷ Serious symptoms of mental illness were reported in three percent of women and two percent of men over 65 years of age. A Harris study showed that 60% of patients 18 years of age and older who visited a provider were unable to remember to ask the provider all their questions.⁸

As the population ages, physical limitations begin to influence activities of daily living. It is estimated that 21% of the population 65 years and older have a visual impairment. This includes cataracts, macular degeneration and bifocal glasses which makes viewing a computer screen difficult.⁹ Hearing impairments for people ages 64 to 74 are present in 24% of the population and 40% in ages over 75 years.¹⁰ Arthritis and other rheumatic conditions can limit upper extremity mobility; the CDC reports 60% of the population over 65 years has this functional limitation.¹¹

PERSONAL HEALTH INFORMATION SYSTEM

A personal health record called Personal Health Information Management System (PHIMS) was first developed as part of a telemedicine project to explore home care and home physical therapy following shoulder surgery.¹² A variant was developed for the University of Washington’s (UW) Department of Orthopedics and Sports Medicine to organize self-reported patient histories, and facilitate referral management.¹³ A study of that system concluded that 85% of the participations were satisfied with the usability of PHIMS.⁵ However, the UW Orthopedics Bone and Joint Center’s patients were typically younger, working patients, who had access to healthcare services, and who had experience using computers. Further research was needed to examine the use of PHIMS in an economically disadvantaged and elderly population.

PHIMS displays a single category of health information at a time, and uses large font sizes, and high contrast screens. The first screen is personal demographics including, provider names, insurers and emergency contacts. The next screen contains family history using radio buttons and text boxes. Subsequent screens recorded allergies to medications, environmental factors and foods. Several places allowed for

questions and comments from the patient to their provider. We had the residents bring either their medications or a list of medications to enter on the medication screen and a section of this screen allowed for comments by the residents to the provider about the efficacy of the medication or any side effects. The last screens provided an area for past surgeries and immunization records. At the end of the session each resident was asked if they would like a printed version for use in their residence and another copy to share with family or providers. In August of 2005 a survey was conducted of the 35 participating residents regarding the use of the PHIMS.⁴

METHODS

The design of this project was a descriptive study on the functional usability of a personal health information system in a low-income elderly and disabled population. The subjects for this study were residents of a publicly subsidized housing project (HA). The project housed 170 residents over the 6 month period during which the study was conducted. Recruitment strategies included posters and flyers and an information session presented on two different occasions in the dining room at the HA with approximately 20 residents in attendance each time. To explain the web-based PHR we utilized PowerPoint slides with user friendly terms, large font size, and minimal technical language. The content included the purpose of PHIMS and an explanation of the PHIMS format, security and confidentiality issues, and basic usage, including registration and self-creation of a password. We emphasized that PHIMS was a patient owned and patient managed health record. The health care benefits of PHIMS were outlined for the residents including the potential benefits of a centralized record for any provider they encountered, especially in an emergency situation. We clarified that PHIMS was part of a research study being conducted by faculty from the UW and was approved by the Human Subjects Committee. The graduate nursing students explained their role as assisting the residents in entering their health information in PHIMS. The nurses made themselves available every Thursday for four hours to provide consultation on PHR usage and general health education.

Posters and flyers were displayed at various locations around the HA building which informed the residents of the date and time the nursing students would be available to assist with data entry. Residents who were present at the information sessions and knowledgeable enough to enter their own information into PHIMS did so with no further assistance. Other residents signed up for help from the nurses at the specified times. The social worker at the HA and a few

resident champions for PHIMS were influential in recruiting other residents. Casual conversations with residents also gave us an opportunity to talk about PHRs and ask residents if they would like to participate.

Since computer ownership has been documented as low among the elderly and lower income groups, the UW provided 6 computers and a printer, and the HA provided a private room with broadband internet access to further reduce barriers to access.

Residents who sought help with data entry saw the nurse in a private setting. Once the PHIMS site was accessed the nurse and patient reviewed the UW Consent Form, including the Researcher's Statement, Purpose and Benefits, Procedures, and the opportunity to withdraw from the study at anytime. Also included in the consent form was the statement that their information would be kept private and confidential and the HA would not have access to their health information. The issue of security was very important for the residents of the HA. Being able to live independently is a requirement for housing at the HA, so the residents were very protective of their health information in fear of being evicted if they were not deemed "healthy" enough to live independently.

The residents that needed help with data entry of their health information into PHIMS required approximately 1 hour of the nurse's time and longer if their health history was lengthy or complicated. The hour appointment also gave the nurse an opportunity to assess the resident's knowledge of their health issues and allowed for teaching. Many of the residents needed assistance in answering various questions related to health issues, such as rationale for taking specific medications. The residents were asked to update their PHIMS if there were any changes in their health status, such as new diagnosis or changes in medication. Updating the records with the residents required 5 to 15 minutes of the nurse's time. Forty one residents participated in this study. The PHR system was made available to them, along with assistance in its use by two graduate nursing students and a social worker. The residents agreed to have their usage patterns observed through both the assistants and through electronic logs.

RESULTS

Of the 170 residents in one facility of EHA, 41 were enrolled in this study and data were complete on 38 residents as of March 2006. The mean age of the participants was 69 (range: 49 to 92 years of age), 82% were female, and many had chronic diseases.

Recruitment is ongoing, with up to two residents per week are being enrolled. Since the initiation of this

study 1 resident died, and 7 moved to another location. Two of the patients who moved are still using PHIMS.

Of the 38 residents that participated, 11 had their own computers. Nine of them were able to initially enter and maintain their health information in PHIMS without assistance. The remaining 29 residents were assisted by a nurse or social worker in entering their health information into PHIMS.

Table 1: Residents Requiring Assistance

Barriers	N=38 (%)
Assistance with PHIMS	29 (76%)
Assistance Updating PHIMS	30 (78%)

Access issues, akin to Tang's "environmental barriers," were significant for some patients. Our study did not assess specific instances where access was a barrier. Anecdotally, these instances occurred far more frequently in the portion of the study population who did not own computers. While 11 of the 38 who participated had computers, the remaining 27 non-computer-owning, participants found their access to the computers was limited to hours when the computer room was open. For all participants, access to assistance with data entry was limited by the nurses schedules or the availability of the social worker. We did not capture instances when patients wanted assistance but neither the nurses or social worker were available.

We identified several patient-centered barriers to creating and using a PHR. The most common barriers noted in this population are described in Table 2.

Table 2: Barriers Identified at EHA

Barriers	N=38 (%)
Computer Literate	24 (63%)
Computer Anxiety	22 (58%)
Cognitive Impairment	13 (34%)
Health Literacy	11 (29%)
Physical Impairment	10 (26%)

Computer literacy and computer anxiety were two major barriers in using PHIMS independently in this population. Computer literacy issues were manifest by occurrences such as patients who required instruction to turn the computer on, to use a mouse or keyboard, to log in, or to perform similar tasks. In some cases, residents who used computers had only used them for very specific tasks, such as email. Computer anxiety was used to describe patients who were unwilling to attempt these tasks but who had no evident physical or cognitive barrier.

This study revealed that thirteen of the 38 residents had cognitive barriers that limited their ability to use

the computer. These limitations had an impact on memory and residents had problems accessing the website because of an inability to remember their password, user name or the PHIMS URL. Cognitive impairments as a result of Alzheimer's, dementia, developmental delays, seizures and head injury also affected the ability for the residents to enter or maintain their PHRs.

Health literacy was identified as a barrier in just under a third of patients, manifest by questions about the content in the PHR, including diseases and conditions, medications, terminology, and similar issues.

Physical limitations of the upper extremities were present in 10 of the participating residents. Other physical conditions that affected the use of PHIMS were hearing and vision impairments, which made seeing the computer screen difficult, communicating with the nurse more time consuming, and completing PHIMS more lengthy. Decreased function of the upper extremities from weakness and decreased mobility from cerebral vascular accidents, multiple sclerosis, Parkinson's and arthritis affected the resident's ability to use PHIMS independently.

DISCUSSION

In August of 2005, 35 residents were surveyed on their use of PHIMS. Eighty-two percent of the residents had brought a printed copy of their PHR with them to their provider visit, and anecdotally, 93% of the providers found PHIMS useful. The residents were pleased with PHIMS when they took copies to their physicians, several resident stated that the "Physician had put a copy of PHIMS in the clinic chart". Another resident made a statement "the provider reviewed PHIMS record and added information to the clinic chart". Another resident stated that "during an emergency the Emergency Medical Technicians' appreciated having access to PHIMS print out. Our plan is to gather objective data from the providers to determine the usefulness of the PHR at the point of care.

One significant limitation of this study is also a strength. In addition to being elderly, disabled, or both, the residents of the HA facility all have low incomes. While this introduces a significant bias, which we believe will over represent the barriers found in the general population, this was a deliberate choice. However, there is also selection bias as computer owners are likely to be overrepresented in the study compared to the overall population of 170 residents. While computer owners represented between 1/3 and 1/4 of our study subjects, a significant majority did not have computers.

Although this is a small convenience sample, our findings suggest challenges in meeting President Bush's goal that all Americans will have a PHR by 2015. There may be other groups who will not be able to create or maintain a PHR for similar reasons that were outlined in this study. Will the responsibility to create a PHR fall on the patient or will the healthcare system provide infrastructure to support this type of activity? Will providers or nurses be reimbursed for this type of work? What about citizens who do not have access to health care? Who will help them create a portable, personal health record? Should community centers, churches, libraries, or local schools be involved in the creation of PHRs, and how will this large amount of personal health information be kept private?

CONCLUSION

Elderly and disabled residents of the EHA were able to create and maintain a PHR, although the majority could not do so independently due to computer anxiety and a lack of computer literacy, cognitive and physical impairments, and health literacy. Registered nurses were able to assist the residents in the creation of their PHR's and they were able to utilize the time to improve the residents' health literacy.

A majority of activity in the utilization of PHIMS was recorded on Thursdays when the nurses were assisting the HA residents. Because a majority of the residents needed assistance in creating or updating their PHR's, and the nurses were only available during a 4-hour period every Thursday, HA resident workflow was impacted.

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FURTHER INFORMATION:

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